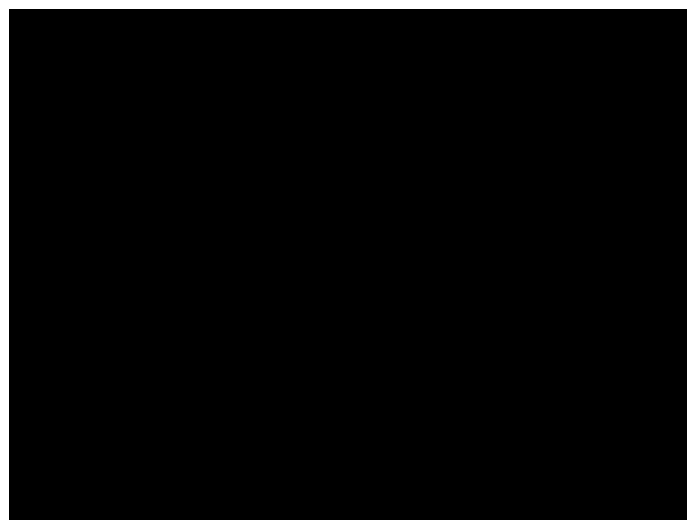


## Research team to visit Horsham

Members of Parkinson's UK research team will be at our September branch meeting to give an insight into the research process and ongoing projects.

It is rare for the team to make such a visit. I don't know how Mike (Onley) persuaded them, but I urge you to come. It's going to be good.



**The meeting is on 1 September 2023, 11:30am to 12:45pm, Mannings Heath Village Hall. Hope to see you there!**

## New: Art Class

A new monthly art class for people with Parkinson's (PWP) will be starting in September at Mannings Heath Village Hall.

The first class will be on 15<sup>th</sup> September, 11:30am to 12:45pm and thereafter on the second Friday of each month.

Recent studies have shown the benefits that art and music therapy can bring to PWP. Music, together with the stroke of a paint brush and the mark it makes, can act as autocues for the brain thus leading to a freeing up of movements. Tremors may stop and a sense of relief can wash over people as they get lost in bright colours and beautiful symphonies.

We start with a warmup exercise to loosen muscles and then hear some stimuli to encourage the creative process.

This may include a poem or a literary piece, the musician will play as everyone can start working on their paintings. Anything can be painted, there's no right or wrong. Shapes, colours, a favourite holiday, a feeling, person or simply fill the page however you feel. We have beautiful loose watercolour inks which work magic on the paper and are fun to have a play with. We hope to mix up the sessions some months with a few mediums, exploring clay as well as silk painting. All materials will be provided.

No art experience is necessary, the aim of the class is to further support people living with Parkinson's and improve their wellbeing as well as bringing a relief to their symptoms. Partners, carers, friends of PWP are encouraged to come to enjoy a relaxing activity. For further details please contact Aimee on 0781 5969267.



### Dates at a glance

- 1<sup>st</sup> September:** branch meeting, 11:30am, MHVH with Parkinson's UK research team
- 6<sup>th</sup> September:** tango, MHVH 7pm
- 14<sup>th</sup> September:** working age group meeting, Lintot pub, 7pm, open to all
- 15<sup>th</sup> September:** art workshop, MHVH, 11:30am
- 4<sup>th</sup> October:** tango, MHVH, 7pm
- 6<sup>th</sup> October:** branch meeting, 11:30am, MHVH, with Maz Castry, singer, song writer
- 12<sup>th</sup> October:** working age group meeting, Lintot pub, 7pm, open to all
- 13<sup>th</sup> October:** art workshop, MHVH, 11:30am
- 28<sup>th</sup> October: Halloween Disco, MHVH, from 7pm**
- 1<sup>st</sup> November:** tango, MHVH, 7pm
- 3<sup>rd</sup> November:** branch meeting, 11:30am, MHVH
- 9<sup>th</sup> November:** working age group meeting, Lintot pub, 7pm, open to all
- 10<sup>th</sup> November:** art workshop, MHVH, 11:30am

*For further details and information on weekly activities see pages 4 and 5*

## Branch news

# Meet Rachael Fairs, Neuro physiotherapist

Rachael Fairs, a neuro physio based at Horsham Hospital, addressed our July branch meeting. She briefly introduced herself then spoke about the work she does with people with Parkinson's (PWP).

Rachael is a mother of three. She originally trained as a geographer, then as a physio – achieving first class degrees in both disciplines so obviously a bright cookie.

She works three days a week for the NHS and 2 days a week seeing private patients at home or in care homes. Before coming to Horsham she worked at St Thomas', London.

She enjoys working closely with the nurse specialists including Stevie Lewis PD nurse specialist. NICE guidelines recognize the

importance of multidisciplinary teams to support people with Parkinson's and early intervention by neuro physios.

Aims of neuro physio: to get in early so as to:

- Build confidence
- Tackle impairments
- Slow deterioration and falls
- Manage stiffness and rigidity
- Postural awareness
- Improve gait, loss of rotation arm swing management of freezing
- Encourage activity
- Address barriers to exercise
- Onward referral.

Rachael emphasized the importance of exercise for PWP. Exercise can help protect existing brain cells and optimize their use through the brain's ability to adapt and change,

She expressed it as “needing an exercise prescription”.

**Optimal prescribed meds + optimal prescribed exercise = optimal management of condition and optimal quality of life and optimal function.**

Ideally the exercise should include something new. If you have always run marathons, continuing to run marathons won't be enough!

Rachael has been on a PD Warrior training course but unfortunately is not licensed to run the programme. (PD Warrior is an exercise programme designed for PWP, for details see July 2023 newsletter.) Rachael was very enthusiastic about it and believes the 10 week course can make a real difference to people. It is designed for the newly diagnosed but she thinks its good for everyone.

## Carer's Support, West Sussex

A representative from Carer's Support, West Sussex also spoke briefly at our July branch meeting.

Carer's Support, West Sussex is a local charity dedicated to supporting unpaid carers. It offers practical and emotional support no matter what the caring circumstance.

It runs Support Groups, a Carer Response Line, helps carers to access equipment to assist them in their caring role, or provide funds so that carers can do something for themselves.

They can also help carers access counselling and call back services, wellbeing support and they have teams in all the of the major hospitals in West Sussex, as well as East Surrey Hospital in Redhill.

For further information go to their website on [www.carerssupport.org.uk](http://www.carerssupport.org.uk) or call 0300 028 8888 or e-mail: [info@carerssupport.org.uk](mailto:info@carerssupport.org.uk)

# Summer Outing – Huxleys Birds of Prey Centre

Report by Cath Stead with photos by Jeremy Collyer

This year our summer outing took us to Huxley's Birds of Prey Centre at Hilliers Garden Centre, followed by tea and a scone in the café.

Friday started rather wet and gloomy but by lunchtime the sun was out and it was HOT. A total of 33 went – so quite a good number.

We were first treated to a rather entertaining flying display with the bird handler explaining what should happen, and the birds (who seemed to be enjoying teasing him) landing or taking off in their own good time.

We watched Yogi(?), a large Eagle Owl I think, as he swooped gracefully from one side of the display ground to the other, landing on poles, or on a perch behind us nearly in the trees.

Then we met two Harris Hawks, Prius and Phoenix, quite different to the owls. They chased a pretend rabbit being pulled across the ground, catching the lures with ease. I was fascinated by the way they shrouded their 'catch' with their wings while they were on the ground.

Lastly we were introduced to a falcon called Pearl. Falcons like to catch their prey in the air

so the handler swung a rope with a treat at the end round and round and the falcon tried to catch the lure, flying well outside the grounds, going behind trees and swooping in out of the sun so the 'prey' could not see him. He caught it after a few goes and it was an impressive sight.

After the demonstration I walked round the aviaries around the site and admired some beautiful birds, all very efficient predators. One of the volunteers was sat in a quiet corner with a little owl on his wrist and answered a wide variety of questions from members of our group. He seemed very knowledgeable about all owls and raptors and I learned a lot.

There was also a slightly different exhibit – a family of meercats, which was a surprise to us all. These were fun to watch with a troupe of babies clambering through a food bowl, and a parent lying flat out on his back, apparently sunbathing!

After a good look around at the various birds we all made our way to the café where we were served with tea and coffee and a very nice large scone with tubs of cream and jam (which comes first??) It took a while for the busy staff to get round to all of us, but I certainly enjoyed my scone and a very nice pot of tea.



## Fund Raising

# Garden Centre Collections

A big thank you to everyone who helped with the collections at Hilliers and Newbridge garden centres. A total of £802 was raised (£276 from Hilliers and a huge £526 from Newbridge). An excellent result.



## **HALLOWEEN DISCO**

*28 October 2023 from 7pm*

### **MANNINGS HEATH VILLAGE HALL**

*Tickets: £12.50*

*Available from  
events@horshamparkinsons.org.uk*

*Licensed bar, nibbles*

*In aid of:  
Horsham branch of Parkinson's UK*

**Date for the diary**

**Race night at Mannings Heath Village Hall**

**Saturday 18<sup>th</sup> November 2023**

**In aid of Horsham branch of Parkinson's UK**

## **Wanted: Santas and Elves!**

The Horsham branch of Parkinson's UK together with the Cuckfield Stroke Group (organised by Carolyn Dodd) have once again been invited to man the Christmas grotto at Upcountry Garden Centre in Scaynes Hill.

This is a fantastic fund raising opportunity. As well as benefitting from the profit of the grotto, if we have enough people, we can also shake a bucket at the exit.

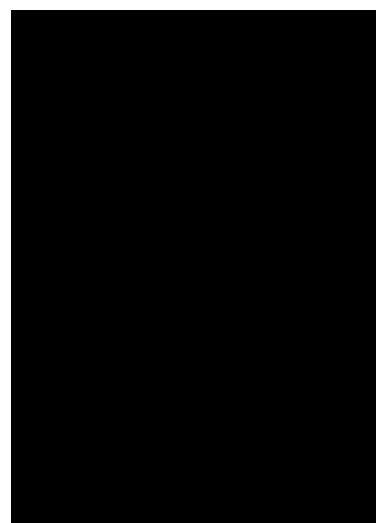
We don't know the exact dates yet (likely to be 4 weekends before Christmas). More information will follow in the November newsletter, but please think about whether you might be able to help.

## **What's on**

### **Monthly Activities**

#### **Branch Meetings**

1<sup>st</sup> September 2023, 11:30 at Mannings Heath Village Hall, representative from Parkinson's UK research team will be giving us an insight into the research process.



6<sup>th</sup> October 2023, 11:30 at Mannings Heath Village Hall with Maz Castrey, singer, song writer

3<sup>rd</sup> November 2023 11:30 at Mannings Heath Village Hall with tba.

**Working Age Group – open to all**

Informal gathering of people with Parkinson's and their partners, second Thursday of the month, from 7pm, at the Lintot pub in Southwater.

For further details please contact Emma Brinton [emma.brinton@sky.com](mailto:emma.brinton@sky.com) or tel 07970 898 740.

#### **Argentine Tango**

First Wednesday of the month, 7pm to 9pm, Mannings Heath Village Hall. All levels of dancers welcome, from complete beginners to experienced exponents. No booking required. No charge. Refreshments served midway through session.



The session will start with tips on how to cope with poor balance and freezing in everyday life. You'd be very welcome for these tips and refreshments only if you're not too keen on dancing!!

For further details please contact Paul Dodd 01403 266 173, e-mail: [doddcp@yahoo.co.uk](mailto:doddcp@yahoo.co.uk)

## Art Workshop

Friday 15<sup>th</sup> September and then the second Friday of every month, 11:30am to 12:45pm, Mannings Heath Village Hall. All welcome, no booking or artistic talent required. The first session will be free thereafter there will be a moderate charge per session, yet to be decided. All materials provided. For further information contact Aimee Bleach tel 0781 5969267 e-mail [aimeebleach@outlook.com](mailto:aimeebleach@outlook.com)

## Weekly Activities

### Monday, Mannings Heath Village Hall, 2pm, Pilates followed by tea, coffee and a chat

Please note this class has very limited capacity to accept anyone new. If you would like to attend, and have prior experience of Pilates, please contact Sue West (tel 01403 273 064) or Barbara Scarborough (tel 01403 891 218) and they will advise you if a place becomes available. Cost £4 per session.

Pilates is essentially a floor-based exercise class. Participants must be able to get to the floor and back up unaided.

**Please note: there will be no Pilates on Monday 4<sup>th</sup> September.**

### Tuesday, Mannings Heath Village Hall, 11:30am, Chair Dancing followed by tea, coffee and a chat

Cost £4 per session. No prior experience or booking necessary, just turn up! Chair dancing is open to all. It is excellent for people with Parkinson's (PWP) and anyone vertically challenged!

**Please note: there will be no chair dancing on Tuesday 5<sup>th</sup> September.**

### Tuesday, Horsham Boxing Club, Horsham Park, 5:15pm Boxercise

Release some of that pent up frustration Parkinson's leaves you with!

Numbers at boxercise are strictly limited. To check on availability or express interest in

attending please contact Emma Brinton [emma.brinton@sky.com](mailto:emma.brinton@sky.com) or tel 07970 898 740. There is no charge for boxercise.

### Wednesday, Mannings Heath Village Hall, 10:30am – 12 midday, Table Tennis

All abilities welcome. Cost £5 per session. Please note this is open to all and is not exclusive to people with Parkinson's.

### Wednesday, Mannings Heath Village Hall, 3:30pm Dance to Live Well followed by tea, coffee and a chat

45 minutes ballet-based exercise followed by refreshments. Suitable for all, PWP and anyone with balance problems. Cost £5 per session, No prior booking or experience necessary.

### Wednesday 5pm and Thursday 5:30pm Physio led exercise classes at Horsham Hospital

Please note: booking is essential. Both sessions are currently full with a waiting list. Please contact Cath Stead for details on 01403 731 072 or 07789 778 094.

### Thursday, Laurie Apted Building, Church Lane, Southwater, 5:30pm, Yoga

Everyone welcome. Cost: £4 per session to be paid in advance in blocks of 6 weeks, by bank transfer.

The number of participants is restricted by the size of the venue. To check on availability or express interest in attending please contact Emma Brinton [emma.brinton@sky.com](mailto:emma.brinton@sky.com). or tel 07970 898 740.

**Please note: there will be no yoga on 21<sup>st</sup> September or 28<sup>th</sup> September.**

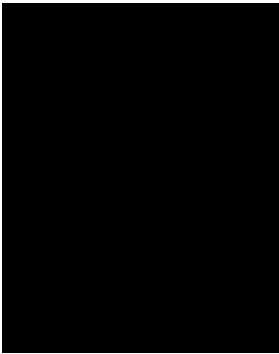
### Friday, Mannings Heath Village Hall, 10:30am, Qi Gong

Everyone welcome. Cost £3 per session. No prior experience or booking necessary, just turn up! May be enjoyed seated or standing.

**Please note: there will be no Qi Gong on 8<sup>th</sup>, 15<sup>th</sup>, 22<sup>nd</sup>, 29<sup>th</sup> September.**

## People News

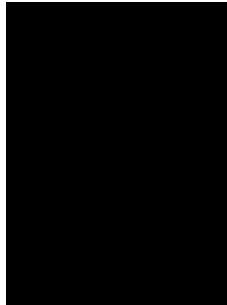
### Mary Cook



It is with great sadness I announce the death of Mary Cook. Mary, wife of Eddy, was a delight to know and I shall miss her. Mary died on 4<sup>th</sup> July after a relatively short fight against cancer.

### Stevie Lewis

Stevie Lewis is expecting her first child and will be off on maternity leave soon. However, there is no need to panic, a replacement for Stevie has been appointed. Stevie has met her and is confident that she'll be great.



Stevie assures me she'll be back – we'll have to wait and see. In the meantime, we wish Stevie all the best.

### Introducing Maija Gray

My name is Maija Gray. I was diagnosed with Parkinson's in 2016 after noticing a tremor in my left hand, and in 2020 just before lockdown I was diagnosed with the early stages of Osteoarthritis in both knees. In late 2022 I noticed my tremor was becoming worse, which was most likely due to 3 years of doing very little exercise and working 4 days a week from home in front of a PC.



Having never met anyone else with Parkinson's and unsure what to expect, I attended my first Working Group session in February this year. I was immediately put at ease and it was great to finally

meet people who could understand some of the same issues I was experiencing. Spending time with the group gave me the confidence to begin exercising again and I now attend weekly Boxercise and Yoga sessions, which I love.

I have helped organise guest speakers or groups for the monthly branch meetings and assist with the street and shop collections. I also helped with

the 3 in 1 event that took place in June this year and I am hoping we can go bigger and better in 2024.

I have been with my partner, Frank for 27 years and we have 2 daughters; Izzy will be entering her fourth and final year at Exeter studying Maths and Ophelia will begin her first year at Derby studying English.

I spent the majority of my career managing National IT Helpdesks and Programming Teams. Any free time and all my holidays were devoted to scuba diving. Frank was an instructor, so I completed the Divemaster and RYA Powerboating courses to help him with training.

We moved to Southwater in 2017, having previously lived in Chichester for almost 20 years. Most of my spare time is now devoted to updating our home, which has needed more work than we originally thought.

I love baking, and according to my family have an unhealthy obsession with gonks, apparently our house has too many, particularly at Christmas!

## Planned building works at Mannings Heath Village Hall

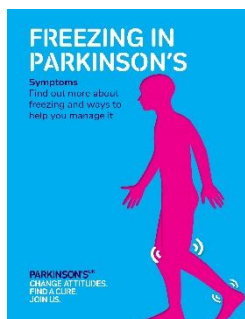
The roof repair and insulation upgrade will start this month (September 2023).. The scaffolding goes up on Tuesday September 12<sup>th</sup> and the work itself will start on Monday September 18<sup>th</sup>. The contractors plan to allow access to the hall throughout the anticipated 4 weeks project but we have to expect noise during our daytime sessions and the venue will be dusty. The latter may make the hall floor slippery so please take care. The car park will also be unavailable for parking.

If any of you struggle with the noise/dirt issues then please speak to your session organiser or speak to Barbara, MHVH Chair directly on 01403 891218. It may be that some groups will prefer to close. Please accept the hall committee's apologies for the disruption but it is a necessary evil. We do need to make the building water tight for the future, and also addition of modern thermal insulation will keep us cosy during the winter months.

# Focus on Freezing

Freezing is a common symptom of Parkinson's. Freezing or "start hesitation" can occur with a variety of activities such as speaking, swallowing, or swimming but is most often associated with walking. People liken it to having their feet 'glued' to the ground. It's unnerving. While your feet are stuck, your head carries on, and the next thing you know you've overbalanced and end up in a heap on the floor.

No-one knows exactly what causes freezing. It occurs when something interrupts the normal sequence of movement. As with most Parkinson's symptoms it often gets worse if you're anxious, stressed or if you lose concentration.



Parkinson's UK produce a 20page booklet see [www.parkinsons.org.uk](http://www.parkinsons.org.uk) (search on freezing)

Unfortunately, there is no magic pill to stop freezing. However, there are a number of strategies to help manage it (reduce the risk of it happening, and to get you going when it has). Whatever you do, don't let freezing stop you doing the things you enjoy!

## How to minimize the risk of freezing

### Self help:

#### Wear the right shoes

Shoes that are easy to slip on may be easier to get on and off but shoes that are too loose and lacking proper support can trigger freezing. Choose supportive and well-fitting shoes with a closed toe and heel.

#### Walk with intent

For most people without Parkinson's, walking is automatic, but with Parkinson's you need to focus more attentively on putting one foot in front of the other. Walking with intent can reduce the risk of freezing.

Pick a target: stand up tall and pick a destination in the distance you'd like to walk to. For example, the end of the hallway or around the bed and into the closet. Say aloud how many steps you think it will take to get there. Start with one large step and count each step you take aloud until you reach your destination.

Create step-overs: If you're able to, place horizontal lines on the floor with painters tape. This can be a great visual aid to cue you where to step in narrow spaces. Aim to step over the line, hitting the floor with your heel.

Focus: cut down on distractions and multi-tasking. Remove rugs and anything else on the floor that could distract you while you walk. Avoid carrying anything in your hands or talking on the phone when you're walking. This will allow you to focus fully on where to place your feet.

#### Keep your feet wide

Freezing is most common when you are turning or changing directions. Typically, your feet end up close together and, thus, your ability to shift your weight from one foot to another is diminished.

When you're turning, imagine you have a small balloon between your feet you don't want to step on. If you're changing directions, do so with a wide stance or your feet staggered one in front of the other.

#### Keep your head up

Try and keep your head up, looking to the horizon. This will encourage an even distribution of weight between the front and back and side to side of your feet. If you look down your weight is likely to shift to your toes. If your weight is in your toes, it can exacerbate festination and freezing.

#### Shake off stress

Freezing episodes are more frequent and intense when you're anxious. Anxiety leads you to tense up which raises stress in your body and feeds your freezing, making you even more anxious! To combat this vicious cycle, deliberately give your body a good shake before you start walking; take a deep breath, stay as relaxed as possible and set out towards your destination!

## Getting Unstuck

The strategies above will help you prevent a freezing episode from occurring, but, what do you do if you find yourself freezing?

The first thing to do when you feel yourself freeze is to stop moving (although this is easier said than done!). This gives you time to refocus on balance, think about your next move and prepare your body to start again, which can reduce any risk of falling.

STOP

STAND TALL

## SHAKE IT OFF

## SHIFT YOUR WEIGHT

## STEP

### Other movement strategies and cueing techniques

- Try another movement – raise an arm, touch your head, point to the ceiling; then re-start
- Change direction: if you can't move forward, try stepping sideways first, and then go forward
- Carry a laser pointer in your pocket; when you freeze – shine the laser in front of your foot and step on the light – this visual cue can help you re-start.
- Visualize an object on the ground in front of you and try to step over it.
- Wear a metronome on your belt or carry a small one in your pocket – turn it on and the external beat can help you re-start.
- Try humming a song and time your re-start with the beat of the music
- Count “1-2-3-go” and then step forward
- Shift your weight from side to side to help initiate taking a step
- March in place a few times and then step forward
- U tube see Jeremy Collyer's videos on <youtube.com@jeremycollyer8095>
- See tango therapy :- on U tube Put in 'Tango therapy in Parkinsons disease'
- basic Argentine tango steps to music



## Research News

# Research Donations

In July the branch sent donations of £2000 each, ie £4000 in total, to support the work of the following two projects.

Project name: Using mice to see how toxic protein moves from the gut to the brain (G-2204)

Led by Professor Maria Grazia Spillantini, at University of Cambridge, from February 2023 to February 2026

Cost: £214,067

Clumps of a toxic protein called alpha-synuclein are commonly seen in the brains of people with Parkinson's, and have been associated with the development of the condition. But it's not clear how these clumps begin to form. One line of research suggests that they might first appear in the gut, before travelling to the brain. Maria and her team will explore how these clumps might move from the gut to the brain, and where else they might go. They also want to see if the bacteria in the gut changes as the clumps form, and whether it could be possible to use this to monitor how Parkinson's is progressing.

Project name: Predicting Parkinson's (PREDICT-PD) (G-2102)

Led by Dr Alastair Noyce at Queen Mary, University of London from December 2021 to December 2024

Cost: £310,792

It's unclear exactly what causes someone to develop Parkinson's, but it's thought to be a combination of genetic and environmental factors. The PREDICT-PD study wants to better understand these risk factors to help identify people who might have a higher chance of developing the condition. The project has already recruited 10,000 people to help identify some of the early signs of Parkinson's. The team will now gather more results from smell tests, DNA collection and finger-prick blood tests. The more we know about the early stages of Parkinson's, the closer we'll be to finding better treatments and a cure.



# Research Roundup

Report by Mike Onley

This month I'm going to focus on the latest research update from Parkinson's UK.

There is potentially exciting news from the NLX112 trial co-founded by Parkinson's UK and the Michael J Fox foundation.

The research aims to develop a drug, which treats dyskinesia often caused by extensive use of levodopa. The trial showed not only promising results with dyskinesia, but also that NLX112 had a positive effect on other motor symptoms of Parkinson's, such as slowness, stiffness and tremor.

NLX 112 targets brain cells that carry serotonin which is known to be important in controlling our movements. This new approach could also help with other research projects to provide a new way to treat motor symptoms.

The next stage of the trial will be to test the drug on a larger scale aiming to find out the best dosage and to confirm the safety and effectiveness of the drug. We are hoping that the drug could be approved and available by 2030.

Another big topic in the research roundup was a blog all about the world Parkinsons congress, which took place in Barcelona in July. I touched on the role of genetics in the last newsletter, and there was a big focus on this at the conference. Large group studies of people with Parkinson's are taking place to look for links between specific genes and certain symptoms and progression rates.

All these research projects require funding, and that's where we come in as a local group.

Parkinson's UK provide a list of research projects and we regularly choose a couple of different ones to fund every six months or so. It is nearly time for us to nominate projects for another round of funding. So next month I will update you on our most recent projects and also on the next ones we are proposing.

Meanwhile, I look forward to seeing you at the research presentation on the 1st of September.

## Contacts

Tom Dellmann chairman, e-mail: [tom.dellmann@gmail.com](mailto:tom.dellmann@gmail.com), tel: 07793 046499

Liz Roberts: branch secretary, 01403 217 263, e-mail [lizroberts.spring@btinternet.com](mailto:lizroberts.spring@btinternet.com)

Dennis Saunders: treasurer & welfare, 01403 259 694, e-mail [dennissaunders888@btinternet.com](mailto:dennissaunders888@btinternet.com)

[Carol Matthews: membership secretary. 01403 263 882 e-mail](mailto:Carol.Matthews@btinternet.com)  
[johnandcarolmatthews@hotmail.com](mailto:johnandcarolmatthews@hotmail.com).

Cathy Stead: exercise groups Horsham Hospital, landline 01403 731072 Mobile: 07789 778094 e-mail [cathstead@yahoo.co.uk](mailto:cathstead@yahoo.co.uk).

Sue West: Monday afternoon activities & newsletter editor tel 01403 273 064, e-mail [westsamilloy@btinternet.com](mailto:westsamilloy@btinternet.com)

Paul Dodd: Tango 01403 266 173, email – [doddcp@yahoo.co.uk](mailto:doddcp@yahoo.co.uk), 8 Lime Kiln Rd, Mannings Heath RH13 6JH

Emma Brinton: working age group, boxercise, yoga e-mail [emma.brinton@sky.com](mailto:emma.brinton@sky.com) tel 07970 898 740.

Stevie Lewis, Horsham Parkinson's Nurse tel 01403 620437 or e-mail [sc-tr.parkinsonsdiseasenurse@nhs.net](mailto:sc-tr.parkinsonsdiseasenurse@nhs.net)

Carole Coupe: PUK Local Advisor, direct dial:0344 225 3668, mobile 07876 455931, e-mail [ccoupe@parkinsons.org.uk](mailto:ccoupe@parkinsons.org.uk). Carole normally works Tuesday, Wednesday, Thursday.